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Quality of care and service trajectories for people with intellectual disabilities: defining the aspects of quality from the client's perspective

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Quality of care and service trajectories for people with intellectual disabilities: defining the aspects of quality from the client's perspective

Background: Care and service trajectories for people with intellectual disabilities (i.e. people with mental retardations) are routes within the healthcare delivery system that consist of all the steps that people with intellectual disabilities and their families have to take in order to realise the needed care and services.

Aim: This article aims to identify the quality aspects of trajectories that are considered important by people with intellectual disabilities and their parents/relatives. In addition, it examines how these aspects are related to quality determinants mentioned in the literature on integrated care and to authoritative models for quality assessment of care and service delivery.

Methods: Quality aspects were collected during eight focus group discussions with people with intellectual disabilities or their parents/relatives. In addition, quality determinants of integrated care and authoritative models for quality assessment were selected by means of a thorough review of the literature. Finally, the quality aspects identified

using focus groups were compared to the determinants and models found in the literature.

Results: The quality aspects presented by people with intellectual disabilities referred particularly to the immediate situation in receiving care and services, such as 'keeping appointments' and 'time and attention', whereas parents/relatives also referred to broader 'organisational issues', such as 'access to support' and 'problems with placement'. The quality aspects, however, are minimally related to the quality determinants of integrated care, probably because clients and their parents/relatives find it difficult to have an overview of the coherence between the various actions that have to be performed, when going through the trajectories. In contrast, the quality aspects seem to fit into the domains of the authoritative models for quality assessment, probably because of the minimal focus of the models on long-term aspects in care and service delivery.

Keywords: intellectual disabilities, quality of care and services, individual care and service trajectories, quality aspects, client's perspective.

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Introduction

Care and service trajectories for people with intellectual disabilities (i.e. people with mental retardations) are routes within the healthcare delivery system that consist of all the steps that people with intellectual disabilities and their families have to take in order to realise the needed care and services. With increasing frequency,

providers of care and services for people with intellectual disabilities institute collaborative relationships with the intention of providing an adequate supply of care and services in response to the requests for help from their clients (1, 2). Collaborative relationships are a necessary condition for clients' individual trajectories within the healthcare delivery system, starting with a request for help and ending with receiving the care and services needed (2). Our previous research (3) shows that individual care and service trajectories in the Dutch situation, in general, follow a 'model route' consisting of five distinct phases:

1 The client and/or his/her parents/relatives become aware that care and/or services are needed and make the relevant requests for help.

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2 In collaboration with professionals, the requests for help will be clarified. Subsequently, it is determined how the requests can be answered best by specific provision of care and/or services.

3 In order to get funding for the needed care and services, often an assessment-based recommendation by a so-called 'indication agency' is applied for. The question as to whether it is necessary to apply for such an assessment-based recommendation and, in case of an affirmative answer, the inquiry which indication agency should actually provide it, depend on the type of requests for help and the particular life domains to which the questions refer. More than one assessment-based recommendation may be required.

4 When the care and/or services applied for are not immediately available, a waiting period or a bridging period of intermediate care follows.

5 The care and/or services needed and applied for are delivered.

User-orientated knowledge regarding quality of care and service trajectories

In recent decades, the attention given to the identification of quality indicators has substantially increased because, amongst other things, this creates the possibility of controlling the quality and consistency of care (4, 5). Quality aspects are specific characteristics that (i) make the quality of care and services measurable and (ii) provide clients with the means to judge the quality of care and services (6). However, in contrast to the ever growing body of system-orientated knowledge concerning quality of care delivered through collaborative relationships, specific user-orientated knowledge regarding the quality assessment of individual care and service trajectories is still largely lacking. To fill this gap, there is an urgent need to enable people with intellectual disabilities and their parents/relatives to report the quality aspects they want to use in judging the quality of their individual care and service trajectories. The identification of quality aspects from the client's perspective is also a prerequisite for future development of assessment instruments (7, 8).

In this research, the client's perspective is considered as the 'client systems perspective', which means that the perspectives of both the people with intellectual disabilities themselves as well as their parents/relatives are taken into account. In recent years, 'the importance of listening to and respecting the wishes of both users and carers has been frequently prioritised' (8, p. 239) in thinking about care and service quality. Moreover, people with intellectual disabilities usually have a less developed capacity for abstract thinking and a less developed level of verbal and linguistic capabilities (9). This makes them dependent on their parents/relatives to represent them. Our preliminary study (3) has shown that parents/relatives actually do play

a considerable role in individual trajectories. Therefore, in such trajectories they can be conceived of as clients themselves.

Care and service quality is often judged by providers or professionals in health care. However, clients' expectations, values and judgements regarding care and service quality often differ markedly from those of providers and professionals (6, 10–12). Therefore, as part of our research on the quality of care and service trajectories from a user's perspective, this article aims to answer the following research question: Which quality aspects of individual care and service trajectories are considered important by people with intellectual disabilities and their parents/relatives?

Existing knowledge of the quality of care and service delivery from a user-orientated perspective

On the basis of the literature it is possible to discuss the quality of care and service delivery from a user-orientated perspective. First, 'integrated care' concerns collaboration and coordination between local and regional institutions from diverse sectors with the intention of decreasing fragmentation and enhancing continuity of care and service delivery (1, 13–15). Departing from this phenomenon, the quality of individual trajectories, from the client's perspective, is determined by the degree of continuity, accessibility, availability and flexibility of care and services, and by the ease of transition between care organisations and care events [e.g. (16, 17)]. However, these aspects are addressed mostly by professionals and not by the reports of service users themselves.

Second, two authoritative models exist that can be used for quality assessment from the client's perspective: the structure-process-outcome model of Donabedian (10) and the SERVQUAL skeleton of Parasuraman et al. (18). However, it should be noted that these models are not directed specifically at individual long-term care and service trajectories. The first model is aimed at the quality of care and services in general. The second model focuses at the quality of single care and service events. This article aims to identify quality aspects that are generated by the reports of the people with intellectual disabilities and their parents/relatives in reference to care and service trajectories. To investigate to what extent the results actually differ from existing knowledge of the quality of care and service delivery from a user-orientated perspective, they are compared with the quality determinants of integrated care, the model of Donabedian, and the SERVQUAL skeleton.

The quality aspects were identified during eight focus group discussions with people with intellectual disabilities and their parents/relatives. They are presented in the third part of this article. In the first and second parts, the quality determinants of integrated care are described and the model of Donabedian and the SERVQUAL skeleton of Parasuraman et al. are introduced. In the fourth part the

quality aspects, which were generated by the focus group members, are compared to the quality determinants of integrated care, the structure-process-outcome model of Donabedian (10), and the SERVQUAL skeleton of Parasuraman et al. (18).

The phenomenon of integrated care

Our preliminary study (3) has shown that integrated care appears to be an umbrella phenomenon that addresses the quality of care and service delivery through collaborative relationships. The quality of individual care and service trajectories from the client's perspective is determined by the continuity, accessibility, availability, and flexibility of care and services. Moreover, it is determined by the ease of transitions between care organisations and care events. Descriptions of these quality determinants are presented in Table 1.

Two models for quality assessment of care and service delivery

People with intellectual disabilities have to rely not only on care, but also on a variety of services (19). The attention to the concept 'service quality' originated in the business sector. Since then, many studies and discourses have expanded this concept [e.g. (11, 20–22)]. In the business sector it is now common practice to define appropriate service quality aspects, and this is also the case in the care sector (10). The similarities between both sectors make it very attractive to make use of knowledge about both quality of care and service quality (20, 23). For example, the quality of both care and services is determined by the relationship between clients and their providers (20). In the next sections, two models for quality assessment of care and services are presented. They will be discussed in relation to the quality aspects of care and services derived from the results of the focus group discussions.

The 'structure-process-outcome model' of Donabedian

The first model is the 'structure-process-outcome model' of Donabedian (10). Donabedian has laid the foundation for quality assessment within the care sector with the development of a model in which he distinguishes three essential elements for the assessment of quality, namely structure, process and outcome. The structure of care is related to 'the relatively stable characteristics of the providers of care, of the tools and resources they have at their disposal, and of the physical and organisational settings in which they work' (p. 81); the structure includes 'the human, physical, and financial resources that are needed to provide medical care' (p. 81). The process of care refers to normative behaviour and is related to the 'set of activities that go on within and between practitioners and patients' (p. 79). The outcome of care is related to the 'change in a patient's current and future health status that can be attributed to antecedent health care' (p. 82–83). However, based upon Dror (24), Donabedian (10) states that an important part of both the process and outcome elements is the procedural outcome, which is the 'plan for patient management, including investigation and treatment' (p. 88). The actual outcome, then, is the effect or impact of the treatment. Osborne (25) has made a comparable distinction: the output is what is actually delivered and the outcome reflects the short-term effect as well as long-term impact on the client (25). Therefore, as care and service trajectories start with a request for help and end when the care and services needed are actually received, the procedural outcome or output element is also important.

The 'SERVQUAL skeleton' of Parasuraman et al.

The second model is the 'SERVQUAL skeleton'. Parasuraman et al. (18) have contributed to the field of quality assessment within the business sector with the development of the SERVQUAL skeleton in which they distinguish

Table 1 Quality determinants of integrated care according to the literature

Description	Quality determinants
Accessibility of care and services	Possibility to have access to the needed care and services provided within the healthcare delivery system in general and to personal care practitioners in specific
Availability of care and services	Possibility to actually receive those care and services of which is determined that it answers the request for help
Flexibility of care and services	Possibility to adjust the individual trajectories to changing needs and circumstances
Seamless transitions (e.g. referrals)	Degree in which the different phases and care events are connected to each other, so that the individual trajectories are integrated
Relational or interpersonal continuity	The enduring relationship between patient and one or more care providers
Informational continuity	The transfer of information about the patient between care events and between patient and care provider
Longitudinal continuity	Sustained follow-up over time with transitions resulting from need
Cross-sectional continuity	The cooperation between care providers and between care provider and patient
Goal continuity	The alignment of the supply of care with the demand for care

five essential dimensions for service quality assessment (18, 20, 26). (i) Reliability refers to the ability of organisations to distribute, actually and accurately, the promised service. Safety and absence of errors and complaints are its most important indicators and (ii) responsiveness is the willingness of organisations to help clients, and to cater to their wishes and needs. The competences of the service provider are its most important indicators; (iii) assurance refers to the relationship of trust and confidence between client and social worker. The knowledge and courtesy of social workers and a relationship of trust are needed to ensure that all relevant information really is brought forward; (iv) empathy reflects the capacity of social workers to take the point of view of clients and to interpret their feelings and emotions and (v) tangibles refers to the available facilities, such as people, equipment and buildings. Accessibility, reachability and entourage are its most important indicators.

It appears that, irrespective of the specific kind of services, customers and clients rely largely on the same criteria for evaluating service quality (18, 20, 26). Therefore, the SERVQUAL skeleton is applicable to the healthcare sector (20).

The focus group research

Methods

By means of focus group research it is possible to explore the experiences, attitudes, opinions, wishes and concerns of people regarding one or more specific issues. The crucial difference with other (group) interview research techniques is that focus groups generate data through interaction between the participants; rather than asking questions systematically, participants are encouraged to talk to each other and to reflect on one another's contributions (27, 28). There are multiple uses of focus groups, such as positioning studies, habits and usage studies, and attitude studies (27). Attitude studies are used to 'determine consumer attitudes toward specific issues, so they (i.e. a company) can design more effective publicity programmes to achieve the objectives of their clients' (27, p. 11). An attitude study is exactly the use of focus group that was carried out for the purpose of this research, because the focus group participants were encouraged to discuss their experiences with and opinions of the quality of care and service trajectories. Providers can use this information collectively in order to design higher quality care and service trajectories.

Composition of the focus groups and the recruitment of the participants. In total eight focus groups were organised: four with people with intellectual disabilities and four with parents/relatives. Authorities in the field of focus group research agree that, in general, a group of 3–12 participants

is acceptable (28, 29). In total, a number of 21 parents/relatives, 14 women and seven men, have participated in focus group discussions of, respectively, six, three, four and eight participants. The children of these participants had diverse types and degrees of intellectual disabilities. The participants were recruited via a nationwide interest group for parents and relatives of people with intellectual disabilities, section Zuidoost Brabant (a region in the Netherlands). All 480 parents/relatives were sent an information letter about the purpose, time and place of the focus group discussions. When interested to participate, they were requested to return a reply card to indicate their preferred times of participation. A number of 38 parents/relatives did return their reply cards. The four data on which the most parents/relatives could participate were selected. After consultation by telephone with the parents/relatives who preferred other times of participation, it appeared impossible to assign nine of them to one of the focus groups. Ultimately, 29 parents/relatives could be assigned to one of the focus group discussions of which 21 did actually appear at the focus group discussions.

A total of 25 people with intellectual disabilities, 11 women and 14 men, have participated in one of the focus group discussions of, respectively, six, five, four and 10 participants. All of these participants had mild-to-moderate disabilities. In order to get insight into the success and failure factors of several independent trajectories, it was prevented that they were related to the participating parents/relatives. In first instance, the participants were recruited with the purpose to compose three focus group discussions with people with intellectual disabilities in the age categories of, respectively, 15–30, 30–45 and 45 years and older, and one focus group discussion with children with intellectual disabilities. However, this only succeeded for the focus group discussion with children; they were all between 11 and 15 years old. At the start of the other three focus group discussions it appeared that the age categories were rather intermingled. This was caused by the replacement of participants who were unavoidably detained and by the unannounced participation of acquaintances of recruited participants. Because of this, the three focus group discussions were composed of people in the age category of 20–60 years old.

In order to obtain information from the intellectually disabled children, a quality game has been developed. The purpose of a quality game is to bring quality aspects to the attention in an imaginative way, for example, in case of the present study by means of a game board with question cards, and to discuss these aspects with the group. In this way, it is easier for the participants to discuss the quality aspects with each other and to give their opinion (30).

The process to recruit the children started with contacting multiple institutes of special education for children with special needs. One school was willing to assist in organising and conducting the focus group discussion with

a group of their students. The parents/relatives of the students concerned received an information letter from their children's teacher accompanied with a reply card to object to, if desired, the participation of their child. The parents/relatives of one of the students did actually object to the participation. Therefore, this child has not participated in the focus group discussion.

The participants of the first mixed focus group discussion were recruited via a nationwide interest group for people with intellectual disabilities. The purpose of the focus group discussion was explained by the coach of the committee members during a general meeting. The members also received an information letter accompanied with a reply card to sign up for the focus group discussion. The participants of the second and third mixed focus group discussions were recruited via the client coach of the board of clients of a regional organisation for care and support for people with intellectual disabilities.

All eight focus group discussions were conducted by a focus group moderator (the first author) and an assistant moderator. The focus group moderator facilitated the discussions by asking open-ended questions and by keeping the discussion focused on the research topic. The assistant moderators made notes of the discussions.

Ethical considerations. With regard to the three mixed focus group discussions with people with intellectual disabilities, no permission for participation has been asked from people other than the participants themselves. The participants from the nationwide interest group were supposed to be able to decide independently on their participation. Concerning the participants from the regional organisation for care and support for people with intellectual disabilities, the client coach was requested to make the decision on the necessity to consult significant others. This appeared not to be necessary.

All focus group discussions, except those with the children and one with parents/relatives, were taped on video. All participants were asked permission to videotape the discussions before the start of each focus group. Furthermore, it was explained that the results would be reported anonymously and that the tapes would be destroyed when the study is finished. The board of directors of the school from which the children were recruited did not give permission to video tape the discussion. Therefore, the discussion between the children was taped on audio cassette. The participants of the other focus group discussions gave permission to video tape the discussions. Unfortunately, due to technical problems, one of the discussions between parents/relatives could not be video taped. Therefore, this conversation was written down in a report.

Analysis of the focus group data. The tapes were transcribed verbatim and all empirical data was coded according to the principles of Miles and Huberman (31). The tran-

scripts were analysed to obtain a framework of the major themes and categories. These major themes and categories were further divided into sub-components, the actual codes, until the set of data was reduced as far as possible. The final codes and corresponding quotations were correlated and recorded using the software program Atlas.ti 4.2 (Berlin, Germany). The original result of the data analysis, performed by the first author, has been checked by two of the other authors, who independently coded a random selection of the transcripts. The differences were discussed and adjustments were made, according to the results of the discussion.

The themes, categories and sub-components were developed, according to the meaning of the data, which means that the data analysis was not merely a matter of sorting the data (e.g. through counting certain terms). The latter also means that it was not decided, preceding the analysis, to use *a priori* concepts when scrutinising the transcripts. However, in order to be sure to obtain a complete overview of relevant quality aspects of care and service trajectories, according to clients and their families, and, thus to prevent that important aspects would be missing, the quality aspects, stemming from the focus group meetings, were compared with the existing knowledge on the quality of care and service delivery.

Results: focus group quality aspects

The set of raw focus group data was divided into 478 quotations. Given the fact that some of the quotations could be attributed to multiple codes, in total 599 quotations were attributed; 317 quotations originated from the focus groups with parents/relatives and 282 from the focus groups with people with intellectual disabilities. Finally, after reflection and recoding, a total of 34 codes, the actual quality aspects, were assigned to the different quotations.

In Table 2 the quality aspects are presented. The table distinguishes between aspects considered important by people with intellectual disabilities, by parents/relatives, or by both groups of participants. This is not to say that the aspects assigned to one of the two groups were not addressed by the other group, but rather that these aspects were addressed considerably more frequently by the group to which they are assigned.

It appears that the quality aspects presented by the intellectually disabled are particularly related to the content of the daily care and services they receive. For example, 'keeping appointments', which refers to the degree to which a personal care provider keeps appointments with his or her client; 'taking wishes and competencies of client seriously' refers to the degree to which personal care providers take into consideration the wishes and competencies of their clients, and 'time and

Table 2 Quality aspects according to the focus groups

<i>Quality aspects by intellectually disabled</i>	<i>Quality aspects by parents/relatives</i>	<i>Quality aspects by both intellectually disabled and parents/relatives</i>
Ambiance and cosiness	Access to support	Composition groups on institution
Food	Burden of care	Integration in society
Friendship	Bureaucracy	Material facilities
Keeping appointments	Capacities/motivation care providers	Mergers and acquisitions in care
Living in an institution	Continuity client/care provider	Transport
Living together in a group	Cooperation between care providers	
Recreation	Cooperation care provider/parents	
Relationship client/care provider	Diagnosis	
Tailor-made care	Fight	
Taking wishes and competencies of client seriously	Financial facilities	
Time and attention	Information provision by care providers	
Volunteers	Personal care (hygiene)	
	Problems with placement	
	Stimulation of development	
	Support	
	Taking wishes and needs of parents seriously	
	Wellness client	

attention' refers to the amount of time and attention an intellectually disabled person receives from his or her personal care providers.

The quality aspects presented by parents/relatives differ from those addressed by the intellectually disabled. Parents/relatives pay attention not only to the content of the care and services received currently, but also to broader organisational issues, such as 'access to support', which refers to the accessibility of supporting services that provide help in following individual paths, 'bureaucracy', referring to the strict compliance to rules and regulations, 'cooperation between care providers', in connection with the benefits of (regional) cooperation between care providers for care and service delivery, 'financial facilities', being the amount of money that parents/relatives and care providers have at their disposal to organise care and service delivery, 'mergers and acquisitions in care', which refers to the direct influence of changes in the care sector on care and service delivery, and 'problems with placement', which refers to the obstacles that have to be overcome before appropriate care and services actually can be provided. In Table 3, for each quality aspect presented above, some illustrative quotations from the transcripts are presented.

Relationship with the existing knowledge

Relationship with the quality determinants of integrated care

It appears that only a limited number of the quality aspects reported in the present study by the focus group partici-

pants (see Table 2) match closely the quality determinants of integrated care: 'access to support' matches 'accessibility of care and services', 'problems with placement' matches 'availability of care and services'; 'bureaucracy' corresponds to 'flexibility of care and services'; both 'cooperation between care providers' and 'cooperation care provider/parents' match 'cross-sectional continuity'. Not surprisingly, all these aspects, which refer to organisational issues, are quality aspects that are presented by parents/relatives. They match closely the system-orientated quality determinants of integrated care.

In the first instance, it also seems that the following aspects match one of the five types of continuity distinguished: 'continuity client/care provider' and 'relationship client/care provider' seem to match 'interpersonal or relational continuity'; 'information provision by care providers' corresponds to 'informational continuity', 'keeping appointments' to 'cross-sectional continuity', 'taking wishes and competencies of clients seriously', 'taking wishes and needs of parents seriously' and 'tailor-made care' to 'goal continuity', and 'time and attention' to 'longitudinal continuity'. However, the respondents did not relate these aspects to trajectories as a whole, but to bilateral relations between separate care providers and themselves.

Relationship to the model of Donabedian and the SERVQUAL skeleton

In the Tables 4 and 5, the quality aspects that were generated by the focus group members, are attributed to the

Table 3 Illustrative quotations from the transcripts

<i>Quality aspect</i>	<i>Illustrative quotation</i>
Keeping appointments	Well, once she [personal care provider; added by authors] was chattering; so, she forgot our appointment. [...] I went to bed, I thought 'suit yourself!'. The next morning she came and asked 'Did we have an appointment?'. I said 'Yes, but you did forget; so, I went to bed, you behaved unsporting'. Well, she did not know what to say. She said that I was a sort of right
Taking wishes and competencies of client seriously	So, I had to do a remittance. You can't do that yourself, she [personal care provider; added by authors] said. I did have the payment order with me; so, please, let me muddle on my own for a moment. Then, she said 'Now you see you can do it yourself!'. Yes', I said, 'then, why did you say I can't do it myself, when in fact I can?
Time and attention	Yes, it happens that you are in need of a chat, but that they [personal care providers, added by authors] do not have time for a chat and say 'Please, come back later'
Access to support	Just like it is organised in Denmark, that's how things work. There you can go to one central place. So, as a parent, you don't have to peddle with your child
Bureaucracy	I was applying for a new assessment-based recommendation. Then, you have to write everything down very precisely, otherwise it will expire. You have to be that precise that you are constantly thinking you must have forgotten something
Cooperation between care providers	Knowledge that is not used very much could then be divided over several care institutes
Financial facilities	So, enough money is invested in care and services, but it is spend on the wrong things
Mergers and acquisitions in care	And now, 12 years later, you constantly see the care organisations changing. They just merge and change. [...] Now, due to the mergers, there are three additional management levels and that 12 to 15 managers have become 40 managers
Problems with placements	But she was the only one who had multiple disabilities. So, I wanted her to move. However, they had no place for her

model of Donabedian (Table 4) and the SERVQUAL skeleton (Table 5). The classification is made by the first author, according to the descriptions of the elements of the model of Donabedian (10) and the descriptions of the dimensions and corresponding indicators of the SERVQUAL skeleton given by Parasuraman et al. (18).

As can be seen in both tables, all elements of the structure-process-outcome model and all dimensions of the SERVQUAL skeleton are filled, to some extent, with quality aspects considered important by the people with intellectual disabilities themselves and their parents/relatives. A large number of quality aspects are attributed to the procedural outcome/output element and the process element of the model of Donabedian, whereas considerably fewer quality aspects are attributed to the outcome element. Furthermore, a large number of quality aspects is attributed to the responsiveness dimension of the SERVQUAL skeleton.

Discussion

The present study has generated three main results. First, the aspects of quality of care and service trajectories that are considered important by people with intellectual disabilities differ considerably from those seen as important by their parents/relatives. Second, the quality aspects generated by the focus group participants are related only to a limited extent to the supposed quality determinants of integrated care. Third, the focus group quality aspects fit

closely into the different domains of two prominent models for quality assessment: the structure-process-outcome model of Donabedian (10) and the SERVQUAL skeleton of Parasuraman et al. (18).

The quality aspects presented by people with intellectual disabilities refer mainly to the content of care and services they currently receive, whereas those presented by parents/relatives refer also to broader organisational issues. This difference is closely comparable with the difference found by Mitchell and Sloper (8) in their study of the quality of services for disabled children and their families. They concluded that 'children and young people's perceptions of valued support services and the criteria by which they assessed 'quality' were firmly grounded in the clubs and activities they attend' (p. 245), whereas 'parents/carers (...) explored broader information and organisational issues' (p. 246). People with intellectual disabilities and their parents/relatives apparently do not just play different roles with respect to individual care and service trajectories, but, partly because of this, they also address and value different quality aspects.

The focus group quality aspects are related only to a limited extent to the quality determinants of integrated care. For instance, the focus group respondents seemed to pay little attention to the continuity of trajectories; in general, they related their experiences to separate care events and not to trajectories as a whole, as they are viewed in the case of integrated care. This might indicate that they have minimal insight into the coherence of the

Table 4 Classification of quality aspects in the model of Donabedian

	<i>Structure</i>	<i>Process</i>	<i>Procedural outcome/output</i>	<i>Outcome</i>
Quality aspects	Access to support	Burden of care	Ambiance and cosiness	Integration in society
	Bureaucracy	Capacities/motivation	Burden of care	Stimulation of development
	Capacities/motivation	care providers	Composition groups on	Tailor-made care
	care providers	Cooperation between	institution	Wellness client
	Continuity client/	care providers	Diagnosis	Integration in society
	care Provider	Cooperation care	Food	Stimulation of development
	Financial facilities	provider/parents	Keeping appointments	Tailor-made care
	Material facilities	Diagnosis	Living in an institution	Wellness client
	Mergers and	Fight	Living together in a group	
	acquisitions in care	Information provision	Personal care (hygiene)	
	Problems with	by care providers	Problems with placement	
	placement	Keeping appointments	Recreation	
		Problems with placement	Stimulation of development	
		Relationship client/care provider	Tailor-made care	
		Support	Taking wishes and competencies	
		Taking wishes and	of client seriously	
		competencies of client	Taking wishes and needs of	
		seriously	parents seriously	
		Taking wishes and	Time and attention	
		needs of parents seriously	Transport	
			Volunteers	
			Wellness client	

separate care events. Furthermore, their experiences were related mainly to events in which they themselves were involved, to bilateral relations between them and their care providers. They hardly spoke about events that happened out of their direct experience, for instance, steps in trajectories taken behind the scenes by care providers. This does not necessarily imply that they did not apprehend anything of these events. It is conceivable that they did not 'see' that these events influenced their quality experience.

It is possible that these observations are caused by the fact that the people with intellectual disabilities, as well as their parents/relatives, were only able to reflect upon their own care and service trajectories and could not compare several trajectories. This probably caused difficulties in gaining an overview of the coherence between actions that had to be performed when going through the trajectories. Consequently, they had difficulties in obtaining a complete picture of the various failure and success factors. Our preliminary study (3) has shown that the bottlenecks, which, according to professionals in the field of the people with intellectual disabilities, exist in individual trajectories closely match the factors that, according to literature, determine the quality of trajectories. This means that views on the quality of trajectories of people with intellectual disabilities and their parents/relatives differs considerably from those of professionals as well as researchers. This might be caused by the fact that the complete insight into the coherence of trajectories, that professionals and

researchers are presumed to have, is lacking in people with intellectual disabilities and their parents/relatives.

During the focus group sessions the steering of the respondents to discuss specific topics was minimal. On the one hand, this has been advantageous because, as a consequence, only those aspects came up that respondents themselves thought to be important. On the other hand, it had the possible disadvantage of making it impossible to direct their attention specifically to trajectory-related issues in order to elicit the identification of more coherence-related aspects.

The focus group quality aspects fit closely into the different categories of the structure-process-outcome model and the SERVQUAL skeleton. A large number of quality aspects is attributed to the procedural outcome/output element and the process element of the model of Donabedian. Both observations are comprehensible: the aspects mentioned by the people with intellectual disabilities are related to the content of care and services and, therefore, assigned to the procedural outcome/output element, whereas the aspects reported by parents/relatives also are related to organisational issues and, therefore, are assigned to the process element. On the other hand, only a few aspects are attributed to the outcome element. This is due to the fact that care and service trajectories end with the delivery of care and services and are not primarily concerned with the change in health status. A large number of quality aspects is attributed to the Responsiveness dimen-

Table 5 Classification of quality aspects in the SERVQUAL skeleton

	<i>Tangibles</i>	<i>Reliability</i>	<i>Responsiveness</i>	<i>Assurance</i>	<i>Empathy</i>
Quality aspects	Access to support	Burden of care	Ambiance and cosiness	Cooperation care provider/parents	Diagnosis
	Bureaucracy	Capacities/motivation care providers	Capacities/motivation care providers	Information provision by care providers	Relationship client/care provider
	Capacities/motivation care providers	Composition groups on institution	Composition groups on institution	Relationship client/care provider	Taking wishes and competencies of client seriously
	Continuity client/care provider	Fight	Cooperation between care providers		Taking wishes and needs of parents seriously
	Financial facilities	Keeping appointments	Cooperation care provider/parents		
	Food	Problems with placement	Fight		
	Material facilities	Stimulation of development	Food		
	Personal care (hygiene)	Transport	Information provision by care providers		
	Problems with placement	Volunteers	Living together in a group		
	Volunteers		Personal care (hygiene)		
			Recreation		
			Stimulation of development		
			Support		
			Tailor-made care		
			Taking wishes and competencies of client seriously		
			Taking wishes and needs of parents seriously		
			Time and attention		
			Volunteers		

sion of the SERVQUAL skeleton. This observation can be easily understood; the aspects that address the direct interaction between client and care provider and the content of care and services, to which most aspects refer, fit best into this particular dimension.

It has been noted that both the model of Donabedian and the SERVQUAL skeleton are not directed specifically at individual long-term care and service trajectories. This is not to say that both models do not pay any attention to concepts such as continuity of care; the model of Donabedian emphasises its importance, when referring to the process element (10) and the SERVQUAL skeleton makes note of it under the Responsiveness dimension (20). However, in neither model there is room for the specific emphasis on aspects related to integrated care that are of special importance for quality assessment of care and service trajectories. This might be the reason that the focus group quality aspects do fit closely into both models, because the people with intellectual disabilities and their parents/relatives seem to have minimal insight into the coherence of trajectories.

Several insights are to be gained from these three main results. First, the results underline that it is important to involve people with intellectual disabilities and their

parents/relatives in the preparation of the quality assessment of trajectories because their views on quality differ from those of professionals and researchers. Second, people with intellectual disabilities and their parents/relatives have to be approached separately during the preparations for quality assessment and during quality assessment itself, because they value different quality aspects of trajectories. Third, during quality assessment it also seems important to include the quality determinants related to integrated care. As people with intellectual disabilities and their parents/relatives appear to have difficulties getting an overview of the coherence of trajectories; it is important that their attention is drawn to these issues and that they are encouraged to assess them. Based upon the stories they told during the focus groups, it is reasonable to conclude that the quality determinants related to integrated care do play an important role during trajectories; the respondents, however, did not recognise or name them as such.

The focus group quality aspects will be used to develop an assessment instrument for the quality of care and service trajectories, consisting of a paper-and-pencil questionnaire for parents/relatives and a face-to-face interview for people with intellectual disabilities. This instrument will provide clients and their parents/relatives

with the possibility to judge the quality of their individual care and service trajectories from their own perspectives. The quality aspects collected during the focus groups and the quality determinants related to integrated care will form the input for the questions of the assessment instrument. The items that refer to the quality determinants of integrated care will be phrased in accordance with the stories told during the focus groups, so that the respondents are able to 'recognise' these questions in their own trajectories.

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Author contributions

Anna Barelds is the first author of the paper. Dr Ien van de Goor was involved in the study design, data collection and analysis, drafting and revision of manuscript and provided supervision. Prof. Dr Guus van Heck was involved in the revision of the manuscript. Prof. Dr Jos Schols was involved in the study design, drafting and revision of manuscript and provided supervision.

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